

The Extent and Impact of Dementia Care: Unique Challenges Experienced by Family Caregivers

Marcia G. Ory, Ph.D.
National Institute on Aging
Jennifer L. Yee, Ph.D.
University of Pittsburgh

Sharon L. Tennstedt, Ph.D.
New England Research Institutes

Richard Schulz, Ph.D.
University of Pittsburgh

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Caregiving is a family issue, as evident by the much cited fact that the bulk of care for chronically ill or disabled older people is provided by family and friends (e.g., Schulz & O'Brien, 1994). This is especially true when considering care for persons with dementia. With the aging of the population, the number of people with Alzheimer's disease and related disorders is expected to increase from nearly two million Americans age 65 and over afflicted with the disease in 1995 to nearly three million people by the year 2015 (General Accounting Office, 1998). The personal, social, and financial impacts of dementia caregiving have been well documented (Schulz, O'Brien, Bookwala, & Fleissner, 1995), with a recent study providing more precise estimates on the costs of both family and institutional care at different stages of illness (Leon, Cheung, & Neumann, in press).

Given the characteristic cognitive, behavioral and affective losses associated with the progression of the disease, caring for someone with dementia is assumed to be more difficult and burdensome than caring for loved ones with other chronic conditions and disabilities (Light, Niederehe, & Lebowitz, 1994). However, this assertion has never really been adequately examined in a large representative population of caregiving including both dementia and nondementia caregivers.

Recent innovations- such as the development of new cognitive enhancing drugs or the emergence of new residential care facilities-are likely to affect the course and care of people with dementia. Similarly with a rapidly expanding population of older adults,

smaller family sizes and more women in the paid labor force, there are concerns regarding the availability and willingness of future generations of family caregivers (Hooyman & Gonyea, 1995; Kaye & Applegate, 1990; Marks, 1996). However, functional deficits are still likely to occur, particularly at the later stages of the disease, and there is no reason to believe that, for the foreseeable future, families will not remain primary caregivers throughout most of the course of illness.

The purpose of this introductory chapter is to provide an overview on the prevalence of caregiving in general, with specific attention to dementia caregiving. Discussing the implications of different definitions of caregiving, we will review national data describing who is providing what kinds and how much care. Also summarized will be the various impacts associated with caregiving tasks and responsibilities. Using data from the 1997 National Survey on Family Caregiving, differences between dementia and nondementia care will be highlighted. The chapter will introduce major research and policy themes which will be further elaborated in this volume.

Health Effects of Dementia Caregiving

The extent to which caregiving affects the physical and mental health of the caregiver is an important policy question and has been addressed by numerous studies carried out in the past decade. Research on caregiving remains a priority because of the need to strengthen family members' abilities to provide care without jeopardizing caregivers' own health or well-being or relinquishing their caregiver responsibilities prematurely (Schulz & Quittner, 1998).

Researchers have assessed psychiatric morbidity attributable to caregiving by using a standardized self-report measures such as the CES-D (Radloff, 1977) or Beck Depression Inventory (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961), structured diagnostic interviews, such as the Diagnostic Interview Schedule (DIS) or the Hamilton Depression Rating Scale (HDRS, Hamilton, 1967), as well as indicators of psychotropic drug use (see Schulz et al., 1995). On the whole, studies using self-report inventories show a consistent pattern of increased depression and anxiety symptomatology among dementia caregivers when compared to age and gender based norms (e.g., Collins & Jones, 1997; Haley et al., 1995; Irwin et al., 1997; King & Brassington, 1997; Majerovitz, 1995; MaloneBeach & Zarit, 1995; Rose-Rego, Strauss, & Smyth, 1998; Schulz et al., 1997). Studies that include clinical diagnoses as an outcome report elevated rates of major depression among dementia caregivers when compared to age-matched controls, and in some studies, elevated rates of generalized anxiety (Irwin et al., 1997; Redinbaugh, MacCullum, & Kiecolt-Glaser, 1995; Vitaliano, Russo, Scanlon, & Greeno, 1996; Vitaliano, Scanlon, Krenz, Schwartz, & Marcovina, 1996; Schulz et al., 1995). The use of psychotropic drugs as an indicator of psychiatric morbidity has been examined in only a few studies and the results have varied widely, making it difficult to reach conclusions about the effects of caregiving on the use of these medications (Schulz et al., 1995).

Studies of physical health outcomes among caregivers have used a broad range of measurements, which can be classified into four major types of outcomes: self-rated global health; the presence of chronic conditions, illnesses, physical symptoms, and disabilities; health-related behaviors, medication use, and health service utilization; and

physiological indices (Bookwala, Yee, & Schulz, 1998). In contrast to the consistent findings for psychiatric health effects among ADRD caregivers, findings based on physical health outcomes are less conclusive.

A common assessment of physical health status that has been employed in caregiving studies is a single question that asks respondents to rate their current overall health on a scale from poor to excellent. In general, most studies have found that caregivers perceive their health to be somewhat poorer than noncaregivers or community samples (Beach, Schulz, Yee, & Jackson, 1998; Mui, 1995; Pruchno, Peters, & Burant, 1995; Rose-Rego et al., 1998; Schulz et al., 1997).

Contrary to the findings for self-rated global health, findings concerning the other types of physical health measures are more equivocal. With respect to self-reported physical illness and disability, common measures employed by researchers include symptom checklists such as the Cornell Medical Health Index or the Physical Health Section of the OARS (Duke University, 1978), and asking respondents to report if they have experienced various illnesses or diseases. A few recently published studies suggest that caregiving may be related to the presence of illness, physical symptoms, and disabilities (Bass, Noelker, & Rechlin, 1996; Canning, Dew, & Davidson, 1996; Cochrane, Goering, & Rogers, 1997; Fuller-Jonap & Haley, 1995; Jutras & Lovie, 1995). For example, Fuller-Jonap and Haley (1995) reported that caregiving husbands reported more respiratory problems than a comparison group. Jutras and Lovie (1995) noted that more caregivers than noncaregivers reported having diabetes and back problems than those that did not reside with a disabled elder. In addition, Cochrane et al. (1997) reported that caregivers mentioned having more physical health problems in the previous year, and more "limited activity days" and "days that required extreme effort" compared to noncaregiving controls. However, in contrast to these studies, other studies have failed to find an association between caregiving and self-reported illness or disability (Brodaty & Hadzi-Pavlovic, 1991; Irwin et al., 1997; Pruchno et al., 1995; Shaw et al., 1997).

With regard to health-related behaviors, some studies have found that caregivers report less physical activity, and sleep and rest than noncaregivers (Burton, Newsom, Schulz, Hirsch, & German, 1997; Fuller-Jonap & Haley, 1995; Glaser & Kiecolt-Glaser, 1997; Kiecolt-Glaser, Glaser, Gravenstein, Malarkey, & Sheridan, 1996; Schulz et al., 1997). However, inconsistent evidence found with regard to differences in other health-related behaviors, such as alcohol consumption, smoking, weight change, finding time to see the doctor, and missing doctor's appointments. In terms of medication use, Schulz et al. found increased medication use among caregivers and Burton et al. reported that caregivers were more likely to forget to take their medications. A few studies examined utilization of health services, such as hospitalizations and physician visits as physical health indicators. However, a consistent association has not been found between caregiving and health care utilization (Schulz et al., 1995).

An important emerging area of caregiving health outcomes research focuses on changes in sub-clinical disease such as immune functioning, hypertension, pulmonary function, blood chemistries, and cardiac arrhythmias as indicators of health status. However,

evidence supporting the association between caregiving and such physiological indices is mixed. In two recent studies, Kiecolt-Glaser and her colleagues reported that compared to matched controls, caregivers showed poorer immune response after exposure to an influenza virus vaccine and to infection by a latent herpes simplex virus (Glaser & Kiecolt-Glaser, 1997; Kiecolt-Glaser et al., 1996). Similarly, Pariente and associates (1997) found that caregivers had lower levels of T cells, a higher percentage of T suppressor/cytotoxic cells, and a lower T helper: suppressor ratio compared to matched controls. With regard to cardiovascular risk factors and functioning, Vitaliano and associates (1996) found that men caregivers had higher lipids than age-and sex-matched control and women caregivers reported less aerobic activity than their noncaregiving counterparts. In addition, Moritz, Kasl, and Ostfeld (1992) showed increased systolic blood pressure among male ADRD caregivers. Although some studies found caregiving to be related to physiological indices of health, others found no association (e.g., Irwin et al., 1997; Schulz et al., 1997).

If we ask the question, what factors predict negative health effects among caregivers, two distinct patterns emerge. One pattern of findings indicates that predictors generally known to be risk factors for negative health outcomes in all populations emerge in these studies as well. Thus, physical and psychiatric morbidity is associated with being female, low financial adequacy, high levels of stress, and personality variables, such as high levels of neuroticism, and low levels of mastery (e.g., Bookwala & Schulz, 1998; Burton et al., 1997; Draper, Poulos, Poulos, & Ehrlich, 1995; Dura, Stukenberg, & Kiecolt-Glaser, 1991; Hooker, Monahan, Frazier, & Shifren, 1998; Morrissey, Becker, & Rupert, 1990; Mui, 1995). Similarly, the relation between depression, anxiety, social support and physical health morbidity have been frequently reported in the literature and are characteristic of the caregiving literature as well (e.g., Li, Seltzer, & Greenberg, 1997; Redinbaugh et al., 1995). The second pattern concerns those associations that are unique to the caregiving context. For dementia caregivers, two factors are important in predicting negative health effects in addition to those already listed above. Patient problem behaviors are consistently linked to both psychiatric and physical morbidity of the caregiver and patient cognitive impairment is consistently related to physical morbidity of the caregiver (Li et al., 1997; Majerovitz, 1995; Moritz et al., 1992; Schulz et al., 1995).

Evaluating links between caregiving stress and health outcomes will ultimately require us to specify complex, multivariate models that are tested prospectively. Minimally, such models will include objective measures of stressors, assessments of how those stressors are perceived by caregivers, and a repertoire of health outcomes that includes categorical clinical disease, sub-clinical disease markers, health care utilization data, and self-reported health. In developing and testing such models, it is important to keep in mind that we must identify not only patterns of relations among variables but also that the observed morbidity effects exceed some absolute standard for classifying an individual as ill or at risk of illness. This can be achieved by selecting health measures with well-established age and gender norms.

In articulating such stress-health models, it may be fruitful to focus on outcomes that reflect the exacerbation of existing health conditions. The demands of caregiving may not precipitate an illness event per se, but rather may aggravate existing vulnerabilities. Thus, attempts should be made to assess whether illness results from existing conditions being exacerbated or represents

new conditions unrelated to prior medical history or risk factors. Illness effects will most likely be found among individuals with elevated risk factors who are exposed to higher levels of stress (Vitaliano, Schulz, Kiecolt-Glaser, & Grant, 1997).

Finally, to the extent that illness effects are observed in future studies of caregiving, it will be important to determine the mechanisms that account for those effects. It must be remembered that mechanisms accounting for symptom reporting, health care utilization, and disease processes may differ from each other.

Definition of Caregiving

As a dynamic process that unfolds and changes over time, the family caregiving role evolves from preexisting social expectations and obligations (e.g. Kosloski & Montgomery, 1993; Stoller, Forster, & Duniho, 1992). Caregiving and care-receiving can occur at any point in the life-course, and is typically associated with chronic illnesses or disabilities which result in losses of independence and functioning. This chapter will draw on studies examining caregiving for older adults, although it is not restricted to caregiving by older adults.

There is no standard definition of family caregiving, which has been used consistently from one study to another (National Alliance of Caregiving, American Association of Retired Persons, 1997 report). What is meant by the term caregiving is not always clear and frequently varies with the purpose for which such definitions are used (Schulz et al., 1997).

The provision of support or assistance by one family member to another is a normative and pervasive aspect of human interactions. Giving help to a family member with a chronic illness or disability is sometimes not very different from the tasks and activities that characterize interactions among families without the presence of illness or disability (Schulz & Quittner, 1998). For example, when a wife provides care to her husband with Alzheimer's disease by preparing his meals or keeping the house clean, she is engaging in an activity she might normally do for her husband. However, assistance with personal care activities, such as bathing or dressing, is more clearly seen as caregiving. The defining difference is that providing help with bathing or dressing or assisting with complex medical routines reflects "extraordinary" care and exceeds the bounds of what is "normative" or "usual" for spousal responsibilities (Schulz & Quittner, 1998). This may help explain why adult children sometimes report more caregiving burdens than do spouses, despite providing fewer hours of actual care.

Whether episodic or chronic, extraordinary care often involves a significant expenditure of time and energy. This may require the performance of tasks that may be physically demanding or unpleasant and disruptive of other social and family roles.

Family caregivers may perform tasks similar to those carried out by paid health or social service providers. Another defining feature of informal caregiving is that family members perform these services for no compensation and do so either voluntarily or because they feel they have no other alternative (Schulz & Quittner, 1998).

While there may be a growing consensus that family caregiving is characterized by some degree of extraordinary care, in reality, different studies have used widely variant definitions of caregiving. Estimates of the prevalence of caregiving and the characteristics of caregivers may vary depending on whether a restrictive or inclusive definition of caregiving is employed (Bookwala et al.1998). We will illustrate the variability in caregiving definitions by presenting two examples: 1) a collaborative intervention study designed to enhance family caregiving, and 2) a national survey designed to document the extent and impact of family caregiving.

REACH

Established in 1995, the Resources for Enhancing Alzheimer's Caregiver Health (REACH) Project was funded by the National Institute on Aging and The National Institute of Nursing Research, NIH to characterize and test the most promising behavioral, social, technological, or environmental interventions for enhancing family dementia care (Coon, Schulz, & Ory, in press). Interventions are carried out at six sites (Birmingham, Boston, Memphis, Miami, Palo Alto, Philadelphia) that have all adopted a common measurement battery.

The modest results of previous caregiver intervention studies are attributed, in part, to the fact that the studies were designed to reduce stress and caregivers who agree to be in studies may not be overly stressed at baseline, or that they may not be performing substantial caregiving tasks (Bourgeois, Schulz, & Burgio, 1996).

Thus, several selection criteria were established to ensure that caregivers were involved in caregiving tasks and experienced caregiving responsibilities that could be taxing. This included requiring that the caregiver be a family member living with the person with dementia; that they had been in the caregiver role for at least six months, and that they provided at least four hours of supervision or direct assistance per day for the care recipient. REACH targeted adult caregivers since it was felt that younger caregivers would be relatively rare and have very different needs. Both genders were solicited except in one site where only women were recruited.

Logistical requirements were also specified with caregivers competent in languages specified by the individual studies, having a telephone, and planning to remain in the geographic area for at least six months. Caregivers were included if they did not have conditions associated with severe disability or death. Additionally, to avoid possible confounding effects, caregivers were not recruited if they were participating in any other caregiver intervention study. It was assumed that some care recipients might be put in new drug studies over the course of the study, and this was to be monitored for its effects on behaviors that might affect caregiver outcomes. While a formal cognitive screen was not conducted on caregivers, if the interviewer reported problems in administering the caregiver screen or interview, a standard protocol was developed for administering a short cognitive assessment.

An underlying theme in establishing these criteria was to minimize the exclusion criteria so that a broad net could be cast for persons with dementia and their primary caregiver. This is important for ensuring generalizability of treatment effects and for easing the recruitment process. Each inclusion and exclusion criterion was presented and defended as absolutely necessary for examining long-term intervention effects.

A National Survey on Family Caregiving in the U.S.

In 1996, the National Alliance for Caregiving, in conjunction with the American Association of Retired Persons, sponsored a national telephone survey of over 1500 family caregivers (National Alliance for Caregiving and American Association of Retired Persons, 1997). The purpose was to document the magnitude, intensity, and types of informal caregiving along with a profile of caregiving impacts in four racial/ethnic groups across the country (Whites, Blacks, Hispanics, and Asians). Given the study purposes, a broad definition of caregiving was utilized to assess the type of informal care provided to older persons. This survey documented the use of a variety of caregiving activities ranging from long-distance care, occasional hands-on care to round-the clock personal care.

The following definitions were used in this study:

“By caregiving, I mean providing unpaid care to a relative or friend who is aged 50 or older to help take care of themselves.”

“Caregiving may include help with personal needs or household chores, It might be taking care of a person’s finances, arranging for outside services, or visiting regularly to see how they are doing. This person need not live with you,” (National Alliance for Caregiving, American Association of Retired Persons, 1997 report, p. 6)

In contrast to the REACH study, this national survey took a very broad view of caregiving and caregivers. The target was an adult caregiver that had provided informal care to a relative or friend at some point during the past twelve months. There were no restrictions on the amount, frequency, duration, or place of care.

The caregivers were asked about the health status of the care-recipients. Those who said they provided care to someone with Alzheimer’s disease, confusion, dementia, or forgetfulness were classified as “dementia” caregivers. A hallmark of dementia care versus care for physical illnesses is the need to provide supervision and cueing to enable the care-recipient to carry out activities of daily living.

Prevalence of Family Caregiving in the U.S.

Estimates of the magnitude and nature of family caregiving will be influenced by the definition utilized. Data from the National Alliance for Caregiving Survey on Family Caregiving will be utilized since this is among one of the largest, most representative family caregiving study conducted to date.

Another major advantage is that this survey is large enough to include both dementia and nondementia caregivers, permitting a comparison of these two types of caregivers on several different dimensions. To date, few studies have been conducted that examined differences between dementia and nondementia caregivers. The results of these prior studies have been inconsistent with respect to the impact of caregiving on dementia versus nondementia caregivers. Some studies have reported few differences between

dementia and nondementia caregivers in terms of burden or depression (Cattanach & Tebes, 1991; Draper, Poulos, Cole, Poulos, & Ehrlich, 1992). In contrast, some investigators have noted that dementia caregivers suffer more negative effects, such as increased depression and anxiety levels, than nondementia caregivers (Hooker et al., 1998; Moritz, Kasl, & Berkman, 1989). However, most of these studies suffered from small sample sizes. In addition, these studies have primarily investigated differences in caregiver's mental health and have not included detailed descriptions concerning characteristics of dementia and nondementia caregivers. Thus, the National Alliance survey provides us with the opportunity to develop a detailed profile of the differences between dementia and nondementia caregivers.

Numbers of Caregivers

Using the entry criteria described above, this study estimated that nearly one in four U.S. households with a telephone contained at least one caregiver. This translates into over 22 million caregiving households nationwide that met these criteria in the past twelve months. The majority of households (approximately 18 million) were White, non-Hispanic. A dementia related condition was reported in more than twenty percent of the households. Nationwide, this translates into over five million households providing care for someone with dementia or related symptoms.

Caregiver Characteristics

This study of caregiving over the life-course found that the typical caregiver was a middle-aged, married woman who was working either full or part-time (National Alliance for Caregiving and American Association of Retired Persons, 1997). As seen in Table 1, several notable differences were observed in terms of demographics between caregivers providing care for persons with dementia as compared to those providing care for persons without this condition. Such differences in caregiving roles (e.g., spousal relationships) have been shown to be important predictors of perceived stress and burden. Dementia caregivers were more likely than nondementia caregivers to be spouses versus adult children (7.2% v. 3.1% spouses; 48.9% v. 52.8% adult children). There were significant differences between dementia and nondementia caregivers in terms of employment status. For example, compared to nondementia caregivers, dementia caregivers were less likely to report being employed full or part-time and more likely to be retired (61.6% v. 68.3% employed; 16.6% v. 10.8% retired). In addition, differences were observed between dementia caregivers and nondementia caregivers with regard to the age of the caregiver and care recipient. Dementia caregivers were significantly older than nondementia caregivers ($M = 46.26$ v. $M = 42.99$) and dementia caregivers were caring for recipients that were significantly older than nondementia caregivers ($M = 78.39$ v. $M = 75.65$). In terms of race, dementia caregivers were over-represented in the Black sample (26.9% v. 18.4%) and under-represented in the Asian sample (10.3% v. 19.4%). No differences between dementia and nondementia caregivers were found with regard to gender, marital status, income, education, and the presence of children in the household.

Table 1 Demographic Characteristics of Dementia and Nondementia Caregivers

Demographic Variable	Dementia Status		
	Dementia	Nondementia	Statistic
Mean Age	46.26 (14.85)	42.99 (14.05)	$t(1496) = 3.65^{***}$
Mean Age of Care Recipient	78.39 (10.10)	75.65 (10.67)	$t(1496) = 4.11^{***}$
Percent Female	72.5	68.1	$\chi^2(1, N=1498) = 2.30$ $\chi^2(3, N=1498) = 21.25^{***}$
Race (percent)			
White	42.8	41.0	
Black	26.9	18.4	
Asian	10.3	19.4	
Hispanic	19.4	20.5	
Relationship to Recipient (percent)	7.2	3.1	Test of dementia vs. nondementia for spouse, parent, or other relationship: $\chi^2(2, N=1494) = 11.65^{**}$
Spouse/Partner	48.9	52.8	
Parent/Parent-In Law	3.1	2.9	
Sibling/Sibling-In-Law	0.0	0.2	
Child	16.9	18.0	
Grandparent/Grand-parent-In-Law	8.8	6.2	
Aunt/Uncle	0.6	0.9	
Other Relative	14.4	16.0	
Non Relative/Friend			
Median Income Category	\$30,000 but less than \$40,000	\$30,000 but less than \$40,000	
Median Highest Education Level	Some College	Some College	
Marital Status (percent)	62.3	63.8	$\chi^2(3, N=1488) = 4.73$
Married/Living with Partner	14.2	17.4	

Single, Never Married	16.5	12.5	
Divorced/Separated	7.0	6.3	
Widowed			
Children Present (percent)	43.5	49.0	$\chi^2(1, N=1488) = 5.21$

Employment status

full or part-time (percent)	61.6	68.3	$\chi^2(2, N=1495) = 8.77^*$
retired	16.6	10.8	
not employed	20.9	21.9	

*** $p < .01$; ** $p < .01$; * $p < .05$

Note: Values in parentheses are standard deviations.

Amount of Care Provided

The typical caregiver in this study had been in a caregiving relationship for about five years. When comparing duration of care and estimated hours of care provided per week between dementia and nondementia caregivers, we see that there is no difference in duration of care, but that there is a substantial difference in amount of care provided. As indicated in Table 2, the average duration of care is about five years for both types of caregivers. However, caregivers providing care for someone with dementia provide over 17 hours of care a week, compared to slightly over 12 hours of care provided by nondementia caregivers.

Table 2 Means of Caregiving Involvement Characteristics For Dementia and Nondementia Caregivers

Caregiver Involvement Characteristic	Dementia	Nondementi a	t-test
Duration of Care (Years)	5.10 (1.28) (N=309)	5.07 (1.28) (N=1122)	$t(1429)=.056$, n.s.
Hours of Care	17.06 (17.37) (N=251)	12.45 (14.54) (N=994)	$t(1243)=4.61^{***}$

*** $p < .001$.

Note: Values in parentheses are standard deviations.

These averages mask the widespread variability in intensity of care reported. At one extreme, there are many caregivers that only provide 8 hours or less of care a week (36.8% of the dementia caregivers and 51.8% of the nondementia caregivers). At the other extreme, there are a significant minority of caregivers who are providing constant care. In this study, dementia caregivers were more likely than nondementia caregivers to be providing such care (16.1% of the dementia caregivers reported providing constant care versus 10.9% of the nondementia caregivers).

Caregiving Tasks

This study provided detailed information on what types of activities caregivers provided assistance with. For example, help may be needed on managing everyday living (e.g., transportation, grocery shopping, housework, preparing meals, managing finances, arranging/supervising outside services, and giving medicine). Assistance may also be

needed with basic activities of daily living, defined as getting out of bed or a chair, dressing, bathing, toileting, feeding, and help with continence or diapers.

Table 3 Means of ADL and IADL and Total Task Performance For Dementia and Nondementia Caregivers			
Types of tasks performed	Dementia (N=320)	Nondementia (N=1178)	t-test
IADL=s	4.78 (1.97)	4.37 (1.83)	t(1496)= 3.47***
ADL=s	2.29 (2.12)	1.36 (1.82)	t(1496)= 7.86***
Total	7.07 (3.22)	5.73 (7.07)	t(1490)= 7.04***
***p ≤ .001.			
<u>Note:</u> Values in parentheses are standard deviations.			
<u>Note:</u>			
ADL=s include: getting in or out of beds or chairs; getting dressed; getting to and from the toilet; bathing and showering; continence or dealing with diapers; feeding.			
IADL=s include:giving medicines, pills, injections; managing finances; grocery shopping; housework; preparing meals; transportation; arranging services.			

As indicated in Table 3, dementia caregivers provided assistance with more tasks overall as compared to nondementia caregivers (an average of 7.07 v. 5.73 tasks performed by each group respectively). Dementia caregivers were particularly more likely to be helping with basic activities of daily living (an average of 2.29 ADL tasks performed by dementia caregivers versus 1.36 tasks performed by nondementia caregivers).

Caregiving Impacts

The duration, amount, and intensity of caregiving tasks have been related to reported stresses and burdens, although studies repeatedly show variability based on caregiver role and other mediating factors. Table 4 summarizes data on reported physical, emotional, and financial strain as well as interference with other activities.

Table 4 The Effects of Physical, Emotional, Financial and Role Stress on Dementia and Nondementia Caregivers			
Item	Dementia Status		
	Dementia	Nondementia	Statistic
	(N=320)	(N=1176)	

Give up vacations, hobbies or your own activities (percent)	55.0	40.9	$\chi^2 (1, N=1496) = 20.30^{***}$
Less time for other family members (percent)	52.0	38.1	$\chi^2 (1, N=1494) = 20.05^{***}$
Other relatives doing their fair share of caregiving (percent)	59.4	74.1	$\chi^2 (1, N=1072) = 19.03^{***}$
Extent of family conflict over caregiving (mean out of a one to three range)	1.55 (0.96)	1.34 (0.76)	$t(1134) = 3.67^{***}$
Emotional strain of caregiving (mean out of a one to five range)	2.99 (1.48)	2.22 (1.36)	$t(1490) = 8.74^{***}$
Physical strain of caregiving (mean out of a one to five range)	2.40 (1.42)	1.80 (1.16)	$t(1490) = 7.72^{***}$
Did you suffer mental or physical problems as a result of caregiving (percent)	22.3	12.6	$\chi^2 (1, N=1494) = 18.66^{***}$
Financial Hardship of Caregiving (mean out of a one to five range)	1.87 (1.34)	1.50 (0.99)	$t(1488) = 5.48^{***}$
Own money spent a month	104.00	106.22	$t(1283) = 0.12$
(mean)			

*** $p < .001$

Note: Values in parentheses are standard deviations.

We see that in general, many caregivers report some negative effects, but that those caring for people with dementia are more likely to report negative effects. The impact on social and personal time is especially notable, with a greater proportion of dementia caregivers reporting having to give up pleasurable personal activities (55% v. 40.9%) or having less time for other family members (52% v. 38.1%). In addition to having less time for other family, dementia caregivers were more inclined than nondementia caregivers to perceive that other family members were not doing their fair share (59.4% v. 74.1%) of caregiving and to report a greater degree of family conflict ($M = 1.55$ v. $M = 1.34$).

In terms of emotional and physical strain, overall, caregivers reported a moderate degree of strain (means are approximately 2 to 3 on a 5-point scale). However, dementia caregivers reported a higher level of emotional ($M = 2.99$ v. $M = 2.22$) and physical strain ($M = 2.40$ v. $M = 1.80$) than nondementia caregivers. Furthermore, dementia

caregivers were more likely than nondementia caregivers to mention that they had suffered mental or physical problems as a result of caregiving (22.3% v. 12.6%), although such caregivers were in the minority. Overall, caregivers reported a low degree of financial hardship (means were between 1 and 2 on a 5 point scale), although dementia caregivers reported higher levels of financial hardship ($M = 1.87$ v. $M = 1.50$) than nondementia caregivers. However, dementia caregivers and nondementia caregivers reported spending about the same amount of money per month on caregiving (approximately \$105 per month).

Overall Feeling

In addition to reporting the amount of strain, family conflict, and interference with other activities resulting from caregiving, respondents were asked to state the one feeling that best describes their caregiving experience. Caregiving was seen in both positive and negative terms, with some differences reported by dementia caregiving status. As indicated in Table 5, more than half of caregivers in this study (both dementia and nondementia) reported positive feelings with regard to caregiving. However, there were significant differences between caregivers and noncaregivers in terms of negative feelings about caregiving. Although anger is not a predominant response, dementia caregivers were more likely to express this feeling (5.1% v. 1.5%) than non dementia caregivers. In addition, related to the results on caregiving strain, a slightly greater proportion of dementia caregivers reported feeling burdened (15.2% v. 10.6%).

To summarize, caregiving had a greater impact on dementia caregivers in terms of time for other activities, family conflict, caregiving strain, the experience of mental and physical problems, financial hardship, and negative feelings. In general, however, most caregivers did not report extremely negative effects as a result of caregiving and many reported feeling positively about their caregiving responsibilities.

Table 5 Percentages of Dementia and Nondementia Caregivers Reporting the Feeling That Best Describes Caregiving

Feeling category	Dementia Status		
	Dementia ($n=237$)	Nondementi a ($n=923$)	Chi-Square
Anger	5.1	1.5	$\chi^2(1, N = 1169) = 11.01^{***}$
Sadness/Fear	2.5	1.5	$\chi^2(1, N = 1169) = 1.19$
Burden	15.2	10.6	$\chi^2(1, N = 1169) = 4.07^*$
Obligation	11.0	12.9	$\chi^2(1, N = 1169) = 0.56$
Love	17.3	18.4	$\chi^2(1, N = 1169) = 0.13$
Happiness	48.9	54.5	$\chi^2(1, N = 1169) = 2.35$

*** $p < .001$; * $p < .05$

Variations in Caregiving Experiences

While the direct relationship between the care recipient's needs for care and the care provided by informal caregivers has been firmly established, the types and amounts of help also have been related to several sociodemographic characteristics of the caregiver. The characteristics frequently investigated include caregiver gender and race, relationship to the care recipient, and coresidence with the care recipient. These factors are related not only to the pattern of care but also to the size and composition of the caregiving network.

Consistently across all studies of caregiving and as has been reported in the NAC study, spouses are the first source of caregiving assistance. Perhaps related to the nature of the marital relationship, spouses are often the sole caregiver (Stone, Cafferata, & Sangl, 1987; Tennstedt, McKinlay, & Sullivan, 1989) and provide the most extensive and comprehensive care (Cantor, 1983; Horowitz, 1985a; Johnson, 1983; McKinlay & Tennstedt, 1986; Shanas, 1979; Soldo & Myllyuoma, 1983; Stephens & Christianson, 1986; Stone et al., 1987). This holds true for caregivers of elders with dementia or with functional disabilities only. Offspring are usually the next source of informal care, also for both groups. However, caregiving for elders with dementia is less frequent among extended kin or non-kin, likely because of the greater commitment and involvement required.

The type and amount of help provided has also been related to the caregiver's gender, again with no difference between caregivers of elders with dementia and those with noncognitive functional disabilities only. Female caregivers provide more help and assist with a wider range of tasks (e.g., Horowitz, 1985b). With gender-specific division of labor, some studies show that male caregivers are more likely to assist with home repairs, financial management, and transportation (Collins & Jones, 1997; Fredriksen, 1996; Young & Kahana, 1989), whereas females provide personal care, meal preparation and other household management tasks (e.g., Dwyer & Coward, 1991; Horowitz, 1985b; Stoller, 1990). However, there is more support in the literature for a gendered division of labor for female-oriented than male-oriented caregiving tasks. Perhaps one exception to this division of labor is the role of spousal caregivers. More likely to be the only source of help, husbands and wives may provide more similar amounts and types of care to their spousal care recipients than adult children provide to parent recipients (Tennstedt, Crawford, & McKinlay, 1993a).

The proximity of the caregiver to the care recipient is a critical factor in determining the pattern of care. In particular, if the caregiver and care recipient coreside, there will be greater caregiving involvement and less use of formal services (Chappell, 1991; Diwan, Berger, & Manns, 1997; Tennstedt, et al., 1993a), regardless of caregiver relationship (Tennstedt et al., 1993a). Coresidence is more likely for dementia caregivers, especially at later stages of disease, which likely accounts for the greater caregiving involvement when compared to all nondementia caregivers. However, the relationship between coresidence and lower use of selected dementia services has also been reported (Gill, Hinrichsen, & DiGiuseppe, 1998). Proximity to the care recipient is less of an issue in the provision of short-term or "crisis" care. Himes and colleagues (1996) have reported no difference in amount of care by those living with or very near the care recipient and by

those caregivers more distant when the care was for a time-limited period. This is less relevant for primary caregivers in the care of elders with dementia, underscoring the importance of proximity or coresidence in the provision of care.

The relationship between race or ethnicity and patterns of care have been studied only more recently. Most of the research on care of minority elders has been conducted with African-Americans and Hispanics. Comparative studies are limited, usually comparing a single minority group with Whites. Connell and Gibson (1997) reviewed 12 studies since 1985 that examined the impact of race, culture, and/or ethnicity on the dementia caregiving experience. Compared to White caregivers, non-White caregivers were less likely to be a spouse and more likely to be offspring, other relative, or friend. Some of the studies included in this review reported that non-White caregivers received more instrumental support from others than did Whites caregivers.

Most of these studies did not report amount of care by White and non-White caregivers. In a study of functionally disabled African-American, Puerto-Rican and White caregivers, Tennstedt and Chang (1998) reported that, controlling for level of disability, non-White caregivers provided more care than White caregivers. Given reports of more strongly held attitudes of filial support among minority caregivers than among White caregivers (Lawton, Rajagopal, Brody, & Kleban, 1992; Cox, 1993; Cox & Monk, 1990), it is reasonable to assume that non-White dementia caregivers also provide more care than do White caregivers, who indicate a greater willingness to institutionalize a care recipient with a dementing illness (Hinrichsen & Ramirez, 1992).

It is commonly thought that the size and composition of the caregiving network influences the organization and provision of care. Larger networks of caregivers, closely related and/or very committed to providing care, are thought to result in sharing of caregiving responsibilities. This would seem particularly relevant in care for elders with dementing illness for whom needs for care are frequently great. The composition of the caregiving network evolves over time, influenced by the age, gender and race of the care recipient, but is generally stable (Peek, Zsembik, & Coward, 1997). Burton and colleagues (1995) have reported that the number of caregivers does not differ by race although others have reported that minority elders have more caregivers due to the involvement of modified extended families (Chatters, Taylor, & Jackson, 1985, 1986; Miller, McFall, & Campbell, 1994; Hatch, 1991; Cox & Monk, 1990).

Yet in light of these data, it has been reported consistently that the primary caregiver provides most of the care. In a study by Stommel and colleagues (1995), which included both dementia and nondementia caregivers, the primary caregiver provided assistance with IADLs almost exclusively, but help with ADLs was shared with others. Data from this study revealed no threshold at which secondary caregivers are involved, but involvement was more likely when a high frequency of care was needed. The primary pattern of division of labor was one of supplementation, i.e., that secondary caregivers shared the responsibility for specific tasks with the primary caregiver rather than a splitting up of tasks (or specialization) among the caregivers. Other data reported by these investigators (Stommel, Given, & Given., 1998) indicate that division of labor is influenced by race. Consistent with the larger caregiving networks of African-

Americans, these caregivers are more likely than White caregivers to share care with secondary helpers but again remain involved in most activities

Interface of Informal and Formal Care

Division of labor also extends to the involvement of formal service providers. This interface between the informal and formal sources of care has been of public policy interest in response to the concern that changing social trends – smaller family size, increased geographic mobility, greater participation of women in the work force, and rising rates of marital disruption – will decrease the availability or willingness of family members to provide care to a disabled elder. Division of formal and informal labor is of concern from a clinical perspective in terms of timely and appropriate use of formal services to ensure the well-being of both care recipient and caregiver.

The involvement of a coresiding caregiver consistently has been related to lower use of formal services by elders with (Gill et al., 1998) and without dementing illness (Tennstedt et al., 1993a; Tennstedt, Harrow, & Crawford, 1996). Initial use, or increased use, of formal services usually occurs in the presence of informal care but when care needs increase or when there is a change in the primary caregiver (Tennstedt, Crawford, & McKinlay, 1993b; Tennstedt et al., 1996). The use of formal services is more likely when the elder has ADL deficits (Diwan et al., 1997). There are no longitudinal data about these transitions in dementia care. Similar to findings for elders with physical disabilities, cross-sectional data indicate that use of formal services is greater by elders with dementia who have greater functional impairment, live alone, and have higher incomes (Bass, Looman, & Ehrlich, 1992; Caserta, Lund, Wright, & Redburn, 1987; Gill et al., 1998; Mullan, 1993; Penning, 1995). Caregiver burden has not been unequivocally established as a correlate or predictor of service use (Bass et al., 1992; Caserta et al., 1987; Gill et al., 1998; Penning, 1995). However, Hamilton (1996) has reported that the primary caregiver's sense of personal competence or caregiving mastery was related to nonuse of services to which they had been referred.

Research Needs

Despite the increase in the magnitude and quality of dementia care research over the past decade, there are still substantial gaps in our knowledge. As discussed throughout this Volume, what is known about dementia and dementia caregiving is heavily influenced by who ends up in our studies. Basic variations in the definition of family caregiver can influence our estimates of the magnitude and impact of dementia care. We are just beginning to address the complexities in untangling the differential effects associated with particular caregiver situations and characteristics across different domains of impact (e.g., personal, social or health impacts).

Too often caregiver research is static. The dynamic aspects of care needs, caregiving roles, and care outcomes need to be examined more fully. We need more attention to how changing disease processes interact with caregiving needs, responsibilities, and available treatments and services. Those who have come to the attention of clinicians and researchers are often providing care for persons at later stages in the disease. Less is known about factors influencing early detection in the community and the process that

family members go through in detecting and labeling dementia related symptoms. Although there has been a recent push to include minority and ethnic populations in dementia research, with few exceptions, most studies are still conducted in primarily white, middle-class populations. Even when minority differences are highlighted for attention, comparisons are typically made across groups, and the more subtle within group differences ignored.

There has been progress in the conceptualization of caregiving impacts, with the development of carefully specified conceptual models linking caregiver stressors to health outcomes. Still needed in most research studies is a clearer delineation of terms such as caregiver roles, responsibilities, stresses, burdens, and impacts. Additional conceptualization and measurement of caregiver outcomes is essential to understand better the natural consequences of caregiving responsibilities as well as to evaluate the impact of interventions designed to ameliorate caregiving burdens. For example, outcome measures should be more sensitive to detecting small changes over time, and assess both positive as well as negative caregiver outcomes. The other chapters in this Volume will describe in greater depth research advances and challenges involved in designing and evaluating the effectiveness of caregiver interventions.

Implications for Policy and Practice

The care of disabled older adults can be burdensome. However, empirical evidence does not support the universality of caregiving stress. For many caregivers of elders with dementia, caregiving is emotionally and physically stressful. Yet, data from some studies of caregivers of elders with functional disabilities indicate that, other than the shared restrictions on personal and leisure time, caregiving is not always perceived as stressful by caregivers (Tennstedt, Cafferata, & Sullivan, 1992; McKinlay, Crawford, & Tennstedt, 1995). From a policy perspective, it is important not to generalize the findings from studies of dementia caregivers to nondementia caregivers and vice versa. Doing so would likely result in over- or under-estimates respectively of the need for support and services. The strains and needs of both groups of caregivers should be acknowledged yet clearly distinguished for at least two reasons: 1) to accurately identify how best to assist caregivers in each group since their stressors, perceived stress, and resulting needs may differ; and 2) to more accurately estimate the demand for long-term care and caregiver support services, both types and amount.

Contrary to the continued concerns of public policy makers, families do not relinquish their caregiving role unnecessarily. Data from a longitudinal study by Tennstedt and colleagues (1993b) support the conclusion that services are used as intended – to support and sustain the informal caregiving arrangement or to fill gaps in needed care. While home and community-based services are used by many, informal care typically predominates in these mixed care arrangements (Tennstedt, Sullivan, McKinlay, & D'Agostino, 1990; Tennstedt et al. 1993b, 1996).

In the case of dementia care, use of formal services is not only appropriate but also clinically indicated as severity increases. From a practice perspective, it is important to determine the optimal mix of formal services and informal care in order to ensure the

well being of both care recipient and caregiver. Transition to a special care environment is another important juncture in this regard. Assistance with appropriate timing and with negotiating a role for continued involvement of the caregiver(s) will facilitate what might be interpreted as another in a series of losses by a caregiver who sees this transition as loss of an important role.

From a policy perspective, the issue of eligibility criteria for services is important. For both publicly and privately (i.e., third party payer) funded services, eligibility typically is based on functional disability in the performance of specified ADLs. The Advisory Panel on Alzheimer's Disease (1989) has advocated for the expansion of eligibility criteria to provide services in situations where the degree of cognitive impairment interferes with the person's ability to complete either IADLs or ADLs without substantial supervision. The cost analyses performed by Paveza and associates (1998) "suggest that changes in cognitive impairment are independent factors affecting cost regardless of the magnitude of ADL/IADL impairment" (p. 79). Similar findings from the National Long-Term Care Channeling Demonstration Project were reported by Liu, McBride, & Coughlin (1990). These findings support the notion of applying a cognitive weighting factor to the degree of ADL/IADL impairment in establishing eligibility for services.

Finally, we should not lose sight of the fact that caregiving is imbedded in the family experience, history, and values. How caregivers respond to the presenting needs for care, how they perceive the personal impact of that care, and how they interface with the formal service system will be shaped by their personal situation. As we have argued for recognition of the heterogeneity of older adults, as researchers, practitioners, and policy makers we must recognize the heterogeneity of their caregivers.